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ABSTRACT

An early intervention program for 14 Down's syndrome children (4 to 15 months old) and their parents included individualized guidance for parents in teaching their infant. Home activities centered on tasks to develop attention: cognitive, perceptual, motor, and language skills. Emphasis was placed on a structured teaching approach with developmental assessments leading to prescribed teaching activities. Task analysis was an important focus. Analysis of scores on the Bayley Scales of Infant Development indicated that Ss scored higher in mental development than infants exposed to little or no intervention and comparably to children in intensive intervention. In motor development, Ss scored significantly better than those receiving no intervention and scored at the top of the range for those who were. (CL)

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BEYOND EXPECTATIONS :

EARLY-INTERVENTION
WITH
DOWN'S SYNDROME INFANTS
AND THEIR PARENTS

PATH/OCCASIONAL PAPER NO.3

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November 1981

ABSTRACT

Between 1978 and 1981, Project PATH at the University of Waikato has been investigating issues and developing materials around the theme of parents as teachers of their handicapped children. One of the major studies undertaken in the project was an early intervention programme for 14 Down's Syndrome children and their parents.

The mean age of the children when they commenced the programme was 8.7 months (range 4-15 months) and the mean age of completing it was 25.5 months (range 15-36 months). In the programme, the families attended a university clinic every two or three weeks, in the course of which the parents (usually the mother) were given individualised guidance in teaching their Down's Syndrome infants. This involved the Project staff working in a partnership relationship with the parents to help them implement a series of structured activities in their homes. These activities focused on perceptual, cognitive, motor and language development and will form the basis of a manual of activities for use by professionals and parents.

The children were independently assessed on the Bayley Scales of Infant Development every three months, the results being compared with those from other studies of Down's Syndrome children. In terms of mental development, the children scored considerably higher than those who had been exposed to no or minimal intervention and achieved results that were around the middle of the range for those reported for children in comparable intensive intervention programmes. With respect to motor development, the PATH children did substantially better than those not receiving intervention and were at the top of the range for those who were.

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Finally, we should like to record our great indebtedness to the fourteen families with whom we have worked during the past four years. We hope they have learned as much from us as we have from them.

David Mitchell

Martha Parker

Robyn Ward.

DISSEMINATION

Progress reports on this study have been presented as follows:

Project PATH. Paper to Early Childhood Care and Development Convention, Christchurch, August 1979 (Published in A. Neale and R. Renwick (eds.). Early Childhood in New Zealand : Their Needs Our Concern).

Project PATH : Parents as teachers of the handicapped. Paper to First National Conference of the New Zealand Association for Research in Education, Wellington, December 1974.

The parent-professional partnership. Invited paper to the Paediatric Section of the XVIth Biennial Conference of the Australian Physiotherapy Association, Canberra, February 1979. (Published in Paediatric Monograph of Australian Journal of Physiotherapy, 1979, 3-13).

Project PATH ; Parents as teachers of the handicapped. Paper to First National Conference on Exceptional Children, Hamilton, May 1980.

Parents ; the untapped resource in special education. Set, Number Two, 1981.

Does early intervention work? A report on Project PATH. Talk to Waikato Council for Exceptional Children, Hamilton, October 1981.

Early intervention with Down's Syndrome children and their parents. Invited paper to Conference on The Child with Special Needs, organised by Otago Postgraduate Medical Society, Dunedin, November 1981.

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CHAPTER ONE

INTRODUCTION

1.1 Review of Literature

Overview. During the last decade or so, early intervention has become increasingly widespread for a wide variety of developmental disabilities (Allen, Holm and Schiefelbusch, 1978; Bricker, Siebert and Casuso, 1980; Chapman and Hillyard, 1981; Clarke and Clarke, 1976; Friedlander, Sterritt and Kirk, 1975; Gibbs, 1981; Mittler, 1977; Tjossem, 1976; Watts et al., 1981). This growth has been reflected in an increasing interest in systematic early intervention programmes in New Zealand (Bridgman and Sims, 1980; Irwin, 1980; Painter, 1981; Straton, 1977).

Parallelling this work in early intervention has been the upsurge of concern with training parents to become more effective in the care and education of their young developmentally disabled children (Gray and Wandersman, 1980; Parker and Mitchell, 1980; Rees, 1978). A number of these programmes have emphasized the role of parents as behaviour modifiers (Berkowitz and Graziano, 1972; Griffin and Hudson, 1978; Johnson and Katz, 1973; O'Dell, 1974). Still others have emphasized training in play techniques (Jeffree, McConkey and Hawson, 1977) or engaging in a task- or skill-oriented training programme (Bricker and Bricker, 1973; Cunningham and Sloper, 1978; Hayden and Dmitriev, 1975; Mitchell, 1981).

Down's Syndrome Studies. Because of the relative ease with which Down's Syndrome infants can be identified at or near birth, they have long attracted researchers interested in such phenomena as the effects of home vs institutional rearing on their development, the variability within the diagnostic category, their apparent intellectual decline over time, and, more recently, the effects of intervention practices on their development. In the remainder of this section, the research bearing on these topics will be briefly reviewed.

There is good evidence that Down's Syndrome children reared at home do better developmentally than those reared in institutions (Carr, 1975; Centerwall and Centerwall, 1960; Ludlow and Allen, 1979; Shipe and Shotwell, 1965; Stedman and Eichorn, 1964). Carr (1975), for example, found that at the age of six months a sample of home-reared Down's Syndrome children scored at an almost identical level to a sample of Down's Syndrome children reared in foster homes or institutions (mental ages of 4.76 months and 4.75 months, respectively, on the Bayley test). By 15 months, however, a gap had opened up between the two groups.

(9.26 months and 7.49 months, respectively), until by 48 months the comparable mental ages were 21.94 months and 16.92 months. There is evidence, too, that Down's Syndrome individuals are far from being a homogeneous entity with respect to their intellectual functioning, even when they have not had the opportunity to participate in intervention programmes (Clements, Bates and Hafer, 1976; Connolly, 1978; Cowie, 1970; Dameron, 1963; Koch and de la Cruz, 1975; Rynders, Spiker and Horrobin, 1978). In a review of 29 studies of Down's Syndrome children over the age of five years in which karyotyping had been carried out and in which a psychometric determiner of educability had been specified, Rynders, Spiker and Horrobin (1978) found a mean I.Q. of 45 for trisomy individuals, but a reported range of 18-75, with similarly large ranges for translocations (28-85 mean 53) and for mosaics (14-100, mean 57). In their own sample of 35 home-reared trisomy children, Rynders, Spiker and Horrobin found that 20 had I.Qs within the 52-68 range and 4 over 68. Three studies suggest that female Down's Syndrome children do rather better than males. In the first of these, Connolly (1978) found a mean I.Q. of 49.9 for females, compared with 41.7 for the males. Clements Bates and Hafer (1976) and Carr (1975) similarly found a sex difference in psychometrically assessed intelligence, both in favour of girls. Although no statistical analysis was possible because of the small sample, Foreman's (1981) data are consistent with these findings. Berry, Andrews, and Gunn's (1980) data, on the other hand, slightly favoured boys.

Down's Syndrome children who have not been involved in intervention programmes show a marked drop in developmental quotients over time (Carr, 1975; Cornwell and Birch, 1969; Cowie, 1970; Dameron, 1963; Dicks-Mireaux, 1972; Ludlow and Allen, 1979; Melyn and White, 1973). Melyn and White (1973), for example, presented longitudinal data on I.Qs for Down's Syndrome children which showed the following: 6 months (58.3), 18 months (58.1), 30 months (54.5), 42 months (54.4), 54 months (49.4). Similar trends, but different levels, were reported by Ludlow and Allen (1979) for a sample of Down's Syndrome infants, with those under 12 months having a mean I.Q. on the Griffiths Scale of 69.4, 61.0 for those between 12 and 24 months and 53.1 for those between 24 and 36 months. Kopp and Parmelee (1979) have summarised the literature on the divergence of developmental quotients between Down's Syndrome children and normals that takes place by the last part of the first year, especially after about 40 weeks, suggesting that the decline is mediated by difficulties experienced by Down's Syndrome infants in processing incoming stimuli and with recognition memory. Compared with normal children, who typically have a surge of cognitive understanding at this age, the Down's Syndrome child is beginning

to show the affects of a "cumulative build up of problems in information processing" (p.43).

The evidence from the growing number of studies on early intervention, however, is seriously bringing into question the inevitability of this rapid decline in the developmental quotients of Down's Syndrome individuals over time - at least during the first few years of life (Aronson and Fallstrom, 1977; Berry, Andrews and Gunn, 1980; Clunies-Ross, 1977; Connolly and Russell, 1976; Cullen et al, 1981; Cunningham, Aumonier and Sloper, in press; Cunningham, Sloper and Berger, 1975; de Coriat, Theslenco and Waxsman, 1968; Foreman, 1981; Hanson and Schwartz, 1978; Hayden and Dmitriev, 1975; Hayden and Haring, 1977; Irwin, 1980; Ludlow and Allen, 1979; Rynders and Horrobin, 1975; Straton, 1981; Thorley et al, 1976).¹

Clunies-Ross (1977), for example, found that after a year in his project the mean developmental level of 19 Down's Syndrome children increased from approximately 50 per cent of their chronological age to a level approximately equivalent to 75 per cent in language, cognitive and social development and to approximately 70 per cent in fine and gross motor development. In the course of a longitudinal study of a group of home-reared Down's Syndrome infants, Cunningham, Sloper and Berger (1975) assessed them every six weeks on the Bayley Scales of Infant Development. Although no deliberate intervention activities were carried out, they found that these regular visits, with parents observing the administration of the tests, seemed to have a facilitatory effect on development relative to earlier studies in which Down's Syndrome children had been assessed less frequently (e.g., Carr, 1975). Ludlow and Allen (1979) compared the performance of two groups of Down's Syndrome infants - an experimental group that attended a developmental clinic or nursery school for at least two years before the age of five and a control group that "developed spontaneously in their own homes". In both groups, there was an initial rapid drop in developmental quotients on the Griffiths Scale during the first three years. In the experimental group, the rate of decline was reduced following the third year while in the control group the decline continued at about the same rate until the fifth year, both groups' quotients flattening out after these ages.

¹Against this general trend, Rees (1981) found that although a programme that utilised parents as language therapists brought about gains in children's receptive and expressive language, these were not matched by scores on the Revised Stanford Binet.

Perhaps the most dramatic results from intervention with Down's Syndrome children has come from the work carried out in the Model Preschool Program at the University of Washington, Seattle (Hayden and Dmitriev, 1975; Hayden and Haring, 1976, 1977; Hayden, Haring and Dmitriev, 1978). In this programme, the infants and their parents came to the centre once a week for a 30 minute individualised training session in early motor and cognitive development. The infants were regularly assessed on the Denver Developmental Screening Test and the Gessell Test, as well as on a Down's Syndrome Performance Inventory. Training goals were based on performances on these tests. One of the principal findings to emerge from a series of studies was that children who did not attend the programme appeared to level off at 61 per cent of normal development, while those who did appeared to level off at approximately 95 per cent. Since these figures are based on the Down's Syndrome Performance Inventory, however, it is not possible to compare them with any rigour with performances on traditional tests such as the Bayley or the Revised Stanford Binet. Although Hayden and Haring (1977) report that the Inventory has a high relationship with other instruments, there is a limited amount of evidence from another study to suggest that high performances on the Inventory may not be reflected in similar performances on the Bayley test. Bridgman and Sims (1980) have reported a rate of progress ratio (developmental gain divided by chronological age gain) of .95 on the Down's Syndrome Performance Inventory over a 10 month period. The corresponding gain on the Bayley test, however, was only .49. Nevertheless, it is clear that the Seattle group has achieved some remarkable results and deserves its reputation for making a major contribution to changed expectancies for Down's Syndrome children.

Because of their comparability with the present study with respect to the age range of the Down's Syndrome children and the use of Bayley test scores as dependent measures, the remainder of this review will concentrate on the procedures of four such studies. The more specific findings will be outlined in Chapter Three.

In the first of these, Cunningham, Aumonier and Sloper (in press) reported on the effects of a Health Visitor visiting the families of 61 Down's Syndrome children in the Manchester area. These visits took place every six weeks from the age of referral in the first weeks of life until 18 months and then every twelve weeks until two years. The curriculum for this intervention programme was based on Cunningham and Sloper's (1978) book. In broad terms, assessments on the Bayley test "compared closely to infants receiving help in other early intervention studies, compared with no treatment controls."

The second study in this group is Foreman's (1981) baby stimulation programme operating out of the Special Education Centre at Newcastle College of Advanced Education, Australia. This programme caters for children from birth to about two years of age and involves the mother and child attending the Centre on a weekly basis with written activities to undertake in their homes. Some of this work was undertaken on an individual basis but the preferred mode of operation has evolved towards children and their parents attending in groups of four or five with teachers and a physiotherapist working as a team with the group. Parent discussion groups are held once a month and every fourth week a home visit by a teacher takes the place of the family's visit to the centre. Data are available for a total of 13 Down's Syndrome children and these will be summarised in Chapter Three.

The third study against which the present one can be compared is Straton's (1977, 1981) Dawnstart Project in Wellington, New Zealand. This is a clinic-based service catering for developmentally disabled infants as soon as possible after their identification until around 30 months. Parents and their children attend once a fortnight for individual work with a psychologist, a physiotherapist and a speech therapist. A visiting therapist is also involved in home visits to assist with self care and mobility. Again, the data on six Down's Syndrome infants whose development has been monitored on the Bayley test will be presented in Chapter Three.

Finally, Berry, Andrews and Gunn (1980) have reported on the performance of a group of Down's Syndrome children on the Bayley test administered every three months for the first year and at six monthly intervals thereafter until a mental age of 20-24 months had been achieved. While they did not work directly with the families in an intervention programme, Berry (1981) has reported that most of the children in the study were involved in one or more such programmes in the Brisbane area.

To sum up, then, the following statements may be advanced regarding Down's Syndrome children: (a) those reared at home do better developmentally than those reared in institutions; (b) there is variability within the intellectual functioning of the Down's Syndrome population - a variability which, even in the absence of systematic intervention, extends to mild levels of sub-normality; (c) the marked drop in developmental quotients over time reported in many studies can be reduced, even arrested or reversed, by appropriate intervention programmes.

1.2 Aims of the Study

The Original contract with the Department of Education was to

Report on the effects on the language and communication patterns of intellectually handicapped children and their parents of a structured language and communication skills programme directed at the children concerned.

This aim was subsequently modified and extended to encompass the following:

1. To move developmentally disabled children's expressive and receptive language cognitive functioning, and motor-perceptual skills closer towards the achievements of normal children of similar chronological age.
2. To provide training for parents of developmentally disabled children to implement a structured programme to achieve the above aim.¹

This report will describe and discuss the ways in which these two aims were fulfilled with respect to 14 Down's Syndrome children and their parents during their participation in Project PATH.

¹As contained in the proposal submitted to the Mental Health Foundation.

CHAPTER TWO

METHOD

2.1 Subjects

The original intention was to work with a range of children who, by the age of 12 months, had achieved a developmental level of from four to eight months. Given the professional background and interests of the staff, it was decided to exclude children with major sensory or physical handicaps. Several factors, however, contributed to changes in this policy of selecting subjects. Firstly, the apparent difficulties experienced by medical personnel in identifying children, other than those with Down's Syndrome, who met these criteria led to a decision to confine the project to Down's Syndrome children and their parents. Secondly, given that such children are usually identified at or near birth, and our feeling that it would be unethical to withhold treatment until the children were 12 months, it was decided to commence intervention as soon as the family had been referred. One of the effects of these decisions was that of the 14 families enrolled in the project, half commenced intervention after the age of 8 months (\bar{X} 12.6 months, range 10-15 months), the other half before 8 months (\bar{X} 5.0 months, range 3-7 months). In the results section, some comparisons of these two groups will be reported, as will comparisons between the 8 girls and 6 boys. The mean age at which the children completed the programme was 25.5 months (range 15-36 months).

Table 1 contains a summary of the other major characteristics of the sample. From this table, it can be seen the mothers were relatively young (\bar{X} 27.7 years, range 19-44 years) at the time of their Down's Syndrome child's birth. With the exception of B5, the only Maori family in the group, the other families were of European origin. There were two solo mothers, neither of whom were employed; of the remaining 12 families the median ranking was '3' on Elley and Irving's (1976) scale of socioeconomic status, with a skew towards the lower levels. Three of the mothers had received five or more years post-primary education, four had received four years, four had received three years and the remaining three had had one or two years. Eight of the children were first-borns, the other six coming from families with two to six children. All except one of the sets of parents had been informed of the presence of Down's Syndrome at or near the time of birth, the one exception (G7) not finding out until their infant was seven months old. The mothers had been informed first in seven of the cases, both parents in six and the father in one case. Three of the children (G3, G8 and B2) have significant heart conditions, one (B6) has mild

vision and hearing disabilities, and one (B4) has some webbing of his fingers. The families lived a mean distance of 90 km from the clinic.

The majority (10) of the families were referred to the project by paediatricians, several of the referrals coming in the first instance from the Child Development Centre of Waikato Hospital. The other four families were self-referrals who had heard about the project. Only three families with Down's Syndrome infants who came to our notice and were offered the opportunity to participate did not do so.

2.2 Procedures

The intervention project had the following features:

- (a) Since the parents were seen as the principal agents of socialising their children, the programme was directed at helping them become more skilled teachers of their children. Emphasis was placed upon a partnership relationship between the professionals and the parents, with the latter being encouraged to suggest teaching strategies and to provide critical feedback on aspects of the programme.
- (b) The programme focused on the following child behaviours:
 - (i) attentional behaviour;
 - (ii) communication skills, including receptive and expressive language;
 - (iii) general cognitive development;
 - (iv) motor and perceptual skills.

The developmental activities used in this programme were evolved in active association with DAWNSTART Project in Wellington (Straton, 1981) and are currently being prepared for publication (see Appendix D for samples of the manual, PATHWAYS).

- (c) With the parents, the emphasis was on a structured teaching approach, with careful and regular developmental assessments leading to the design of 'prescribed' teaching activities and systematic teaching based largely on social learning principles. The parents were taught task analysis procedures to help them design teaching activities beyond those discussed during their clinic visits. Emphasis was placed, too, on generalising their own and their child's clinic-learned skills to the home and other natural environments.)
- The general philosophy of the programme, however, fell short of a

TABLE 1
CHARACTERISTICS OF SUBJECTS

Variable	G1	G2	G3	G4	G5	G6	G7	G8	B1	B2	B3	B4	B5	B6
Mother's age at birth	25	26	25	44	26	32	26	22	19	22	28	35	21	37
Father's age at birth	28	26	31	40	24	54	30	22	21	28	27	40		40
Family's SES ¹	1	5	4	4	5	2	3	4	Solo	5	3	3	Solo	3
Ordinal position of child at birth ²	$\frac{1}{1}$	$\frac{2}{2}$	$\frac{2}{2}$	$\frac{6}{6}$	$\frac{1}{1}$	$\frac{1}{1}$	$\frac{3}{3}$	$\frac{1}{1}$	$\frac{1}{1}$	$\frac{1}{1}$	$\frac{3}{3}$	$\frac{1}{1}$	$\frac{1}{1}$	$\frac{3}{3}$
Birthweight (in grams)	3175	3005	2722	2640	3770	3090	2807	2807	2980	3070	3232	2835	3005	2863
When parents informed	Birth	Birth	Birth	Birth	Birth	Birth	7m	Birth	Birth	Birth	Birth	Birth	Birth	Birth
Which parents informed ³	M	B	B	B	M	B	B	M	M*	M	F	M	M*	B
Physical abnormalities	Nil	Nil	Heart	Nil	Nil	Nil	Nil	Heart	Nil	Heart	Nil	Webbed fingers	Nil	Vision-Hearing
Distance from clinic (in kilometres)	135	90	20	5	20	160	135	55	100	25	190	140	170	5
Age at entry to intervention	15m	15m	4m	6m	4m	6m	7m	10m	12m	13m	12m	3m	11m	5m
Age at exit from intervention ⁴	36m	31m	27m	30m	18m	20m	18m	18m	30m	30m	30m	30m	24m	15m
Mother's Education ⁵	B	C	C	A	A	D	C	D	B	C	B	B	A	D

* Solo parent

¹ Elley and Irving (1976) Index

² Numerator = place in family; denominator = number in family

³ M = mother first; F = father first; B = both together

⁴ Children under the age of 30 months (except G6) will continue a programme under the jurisdiction of the Psychological Service until they reach that age

⁵ A = 1-2 years; B = 3 years; C = 4 years; D = 5+ years at secondary school or higher

- rigorous, data-based behavioural approach of the kind advocated by such writers as Hanson and Bellamy (1977) and Gardner (1976) - mainly because early attempts to introduce such methods resulted in negative feedback from the parents.
- (d) There were fortnightly visits for each family, each of approximately two hours' duration. In the course of these visits, the parents received guidance from a staff member with skills in the educational/psychological area and from a physiotherapist who focused on gross-motor skills.
 - (e) The bulk of the work was carried out in a clinic setting at the University of Waikato (see Appendix B for a plan of the clinic), but there were occasional home visits by the staff to some of the families. These latter visits gave the parents opportunities to demonstrate teaching skills in their own milieu, as well as helping the therapist to become more aware of the home circumstances of the families.
 - (f) For the most part, families attended the clinic one at a time but on occasions appointments were overlapped to provide parents with an opportunity to meet others and occasional group meetings for all the parents were held.
 - (g) Between sessions, parents were given written 'homework' activities to carry out with their Down's Syndrome children on a regular, daily basis. Examples of these activities are included in Appendix C.
 - (h) The children's progress was assessed every three months on the Bayley Scales of Infant Development. These assessments were carried out by an independent psychometrist who was not involved in the teaching programme. The parents were present during the administration of the tests and they were kept fully informed on their child's progress. Reports on the assessments, together with brief summaries of the goals for the ensuing three-month period were sent to the referral agents (see Appendix E).

In addition to the Bayley assessments, shifts in the quality of parent-child interactions were monitored and are in the process of being analysed.

- (i) Some parts of the sessions were videotaped, both to give parents feedback on their own teaching and to act as a means of teaching them certain skills by modelling on other parents' behaviour.
- (j) As children left the programme, the Psychological Service of the Department of Education took responsibility for continuing the interventions until they turned 30 months of age and for carrying out the three-monthly Bayley assessments until five years of age. Prior to that arrangement being made, the project staff facilitated the placement of those who had been discharged from the programme. These placements included regular kindergartens and play centres, the Special Needs Section of the Correspondence School, and facilities run by the Society for the Intellectually Handicapped.

2.3 Data Analysis

In a study of this kind, it is very difficult, if not impossible, to employ an 'untreated' control group, both on ethical grounds and in recognition of the fact that most of the parents who came to the notice of the project would undoubtedly have found some way of enrolling their infant in a programme if the service had been withheld. The large distances travelled by many of the parents testifies to this latter point.

The performances of the children in the project can, however, be measured against those of Down's Syndrome children elsewhere who had either not received any direct intervention (Carr, 1975; Clunies-Ross, 1977; Cunningham and Sloper, 1977; Dicks-Mireaux, 1972; Fishler, 1964) or who had received different patterns of intervention (Berry, Andrews and Gunn, 1980; Cunningham, Aumonier and Sloper, in press; Foreman, 1981; Straton, 1981). Background information on Straton's DAWNSTART subjects is contained in Appendix A.

In order to monitor the developmental shifts that occurred, both in the PATH children and in the comparison subjects, 'gain ratios' were calculated. These ratios were arrived at by comparing the rate of development of the children in the Mental and Motor Scales of the Bayley test between the times of their entry to and exit from the project with their increased chronological age over the same period. In other words,

$$\text{Gain ratio} = \frac{\text{Developmental Age on Exit} - \text{Developmental Age on Entry}}{\text{Chronological Age on Exit} - \text{Chronological Age on Entry}}$$

ata on 19 Down's Syndrome children at 18 months prior to the commencement of intervention.

Data will also be presented in graphic form to show the rate of development of the individual PATH subjects in relation to composite data for studies in which Down's Syndrome children had received no or minimal intervention. These graphs also show a 'target' developmental curve which was set at approximately 75 per cent for the purposes of the project (see Figures 1 and 2).

FIGURE 1

BAYLEY MENTAL DEVELOPMENT - COMPOSITE DATA ON DOWN'S SYNDROME
CHILDREN AND PATH TARGETS

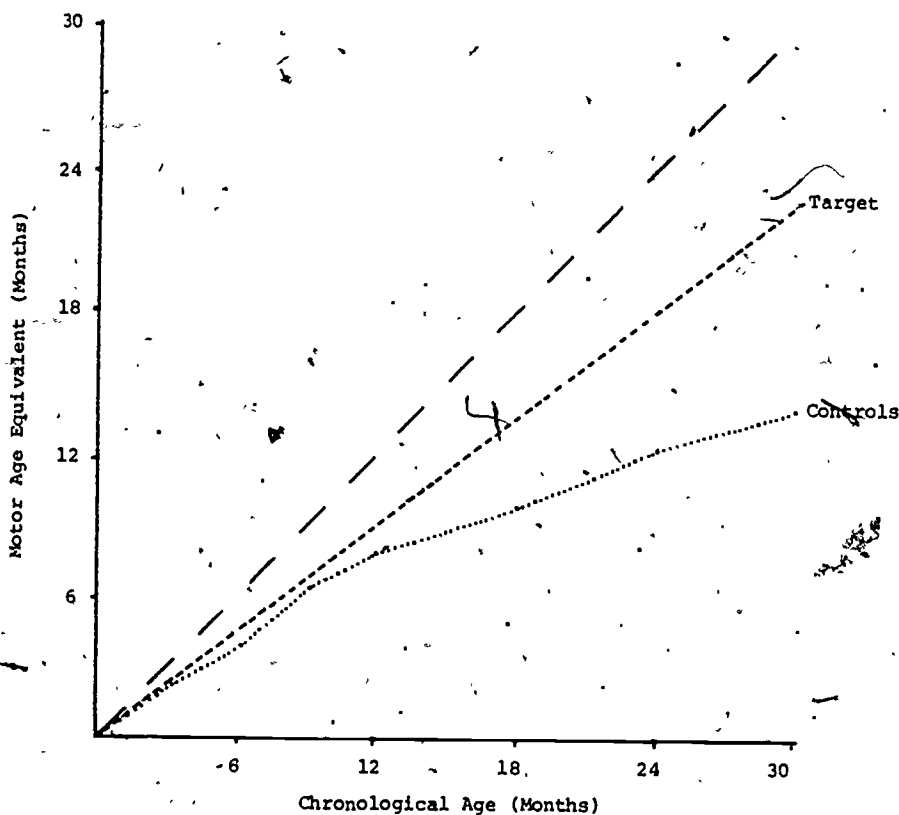
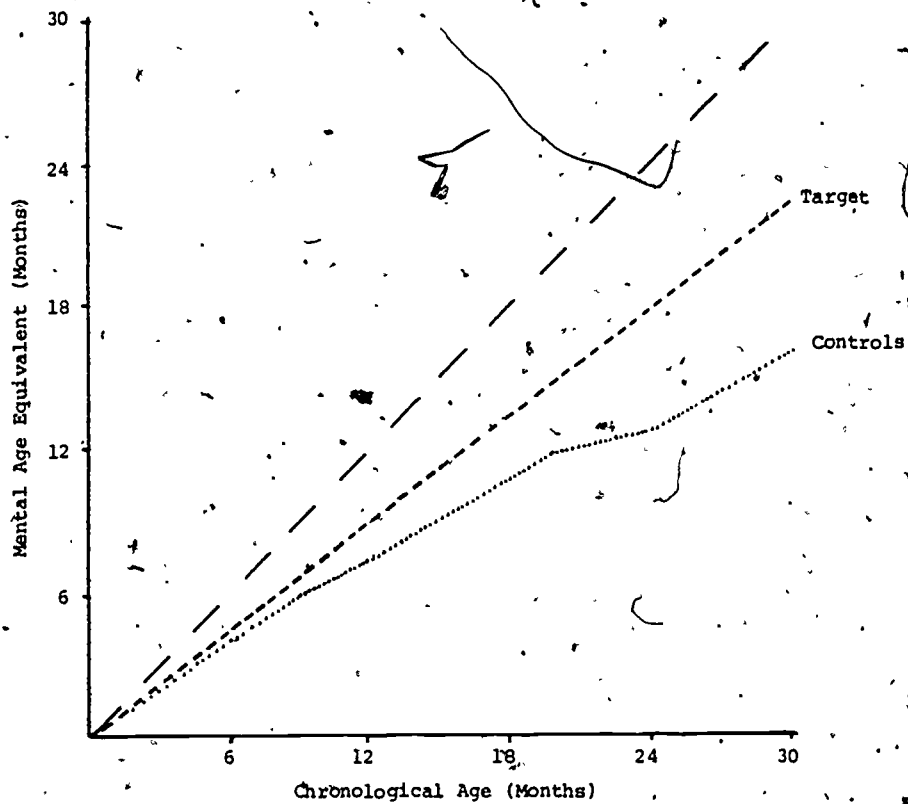


FIGURE 2

BAYLEY MOTOR DEVELOPMENT : COMPOSITE DATA ON DOWN'S SYNDROME
CHILDREN AND PATH TARGETS



CHAPTER THREE

RESULTS

3.1. Mental Development

Table 2 shows the gains achieved by the Down's Syndrome children on the Mental Scale of the Bayley test from the time they entered the programme until they were discharged from it or when it terminated. The mean of the individuals' gain ratios was .70, with a range from .55 (B6) to 1.05 (G7).

TABLE 2

INDIVIDUAL CHILDREN'S ENTRY AND EXIT SCORES
ON BAYLEY MENTAL SCALE : PATH DATA

Subject	Age on Entry	Mental Age Equiv. on Entry	MDI on Entry	Age on Exit	Mental Age Equiv. on Exit	MDI on Exit	Entry-Exit MA Gains/CA Gains	Gain ratio ^a
G1	15	13	84	36	28	75	15/21	.71
G2	15	12	73	31	23	73	11/16	.69
G3	3	2.5	77	27	19.5	63	17/24	.71
G4	6	5	77	30	18.5	50	13.5/24	.56
G5	4	4.5	111	18	13	56	8.5/14	.61
G6	6	6.5	110	20	19.5	97	13/14	.93
G7	7	7.5	115	18	19	107	11.5/11	1.05
G8	10	6	54	18	11.5	<50	5.5/8	.69
B1	12	10	68	30	19	52	9/18	.50
B2	13	7.5	<50	30	19	52	11.5/17	.68
B3	12	9.5	70	30	23	73	13.5/18	.75
B4	3	3	98	30	20	60	17/27	.63
B5	11	8	62	24	17	62	9/13	.69
B6	5	4	80	15	9.5	41	5.5/10	.55
\bar{X}	8.7	7.1		25.5	18.5			.70

^a Gain ratio = $\frac{\text{Mental Age on Exit} - \text{Mental Age on Entry}}{\text{C.A. on Exit} - \text{C.A. on Entry}}$

In order to make the data comparable with those reported by Foreman (1981), a separate analysis was carried out by taking a notional maximum exit age of 24 months. This led to a marginally higher mean gain ratio of .72. When this latter mean is compared with gain ratios achieved by Down's Syndrome children in other research projects (Table 3), it is clear that the PATH subjects' developmental rate was considerably in advance of children receiving no or minimal intervention (.47) and of those receiving various forms of intervention as reported by Berry, Andrews and Gunn (1976) (.59). When compared with children in similar intervention programmes, the PATH subjects scored in the middle of the range bounded by Cunningham, Aumonier and Sloper's (in press) sample (.65) and Straton's (1981) small DAWNSTART group (.86). However, comparisons among the various studies cannot be made with precision for, as can be seen in Table 3, no two samples of Down's Syndrome children were identical with respect to chronological age and mental age at the entry points. For example, Foreman seems to have a very competent group of infants, while Straton's sample¹ was functioning at quite low levels on entry to their respective programmes. While the use of the gain ratio takes these variations into account, it cannot, of course, overcome any lack of initial matching in the samples.

When the mental ages of the children on exit from the various projects are considered in relation to their chronological ages, the PATH subjects (75.7 per cent) scored at a level comparable to DAWNSTART (75.3 per cent) and to Foreman's group (75.1 per cent) and slightly in advance of Cunningham, Aumonier and Sloper's (66.3 per cent) and Berry's (62.2 per cent) groups. At approximately two years of age, all groups were considerably in advance of Down's Syndrome children who had received no or minimal intervention (50.0 per cent).

The above results confirmed the legitimacy of setting a general 'target' of 75 per cent of average development for the intervention project. From Table 2, however, it can be seen that such a target is not always possible of accomplishment when individual children are considered.

TABLE 3

COMPARISONS OF DOWN'S SYNDROME CHILDREN'S SCORES
ON BAYLEY MENTAL SCALE : ACROSS PROGRAMMES

Study	N	Entry			Exit			Gain ratio: ^e		
		\bar{X} C.A. (months)	\bar{X} Mental Age Equiv. (months)	Mental Age Equiv. C.A.	\bar{X} C.A. (months)	\bar{X} Mental Age Equiv. (months)	Mental Age Equiv. C.A.	M	F	T
PATH 1 ^a	14	8.7	7.1	84.9	25.5	18.5	72.6	.63	.74	.70
PATH 2 ^b	14	8.7	7.1	84.9	21.4	16.2	75.7	.67	.76	.72
DAWNSTART	6	5.0	3.2	64.0	21.5	16.2	75.3	-	-	.86
Foreman	13	3.1	3.1	97.6	21.7	16.3	75.1	.66	.88	.78
Berry et al 1 ^c	24	6.9	4.8	78.3	24.4	13.5	60.8	.60	.55	.58
Berry et al 2 ^d	24	6.9	4.8	78.3	20.6	13.0	62.2	.62	.56	.59
Cunningham	61	6.0	4.1	68.3	24.0	15.9	66.3	-	-	.65
Composite ^f	300+	9.0	5.0	55.6	24.0	12.0	50.0	-	-	.47

a Actual data at termination of project

b Data with maximum exit age taken at 24 months

c Actual data

d Data with maximum exit age taken at 24 months

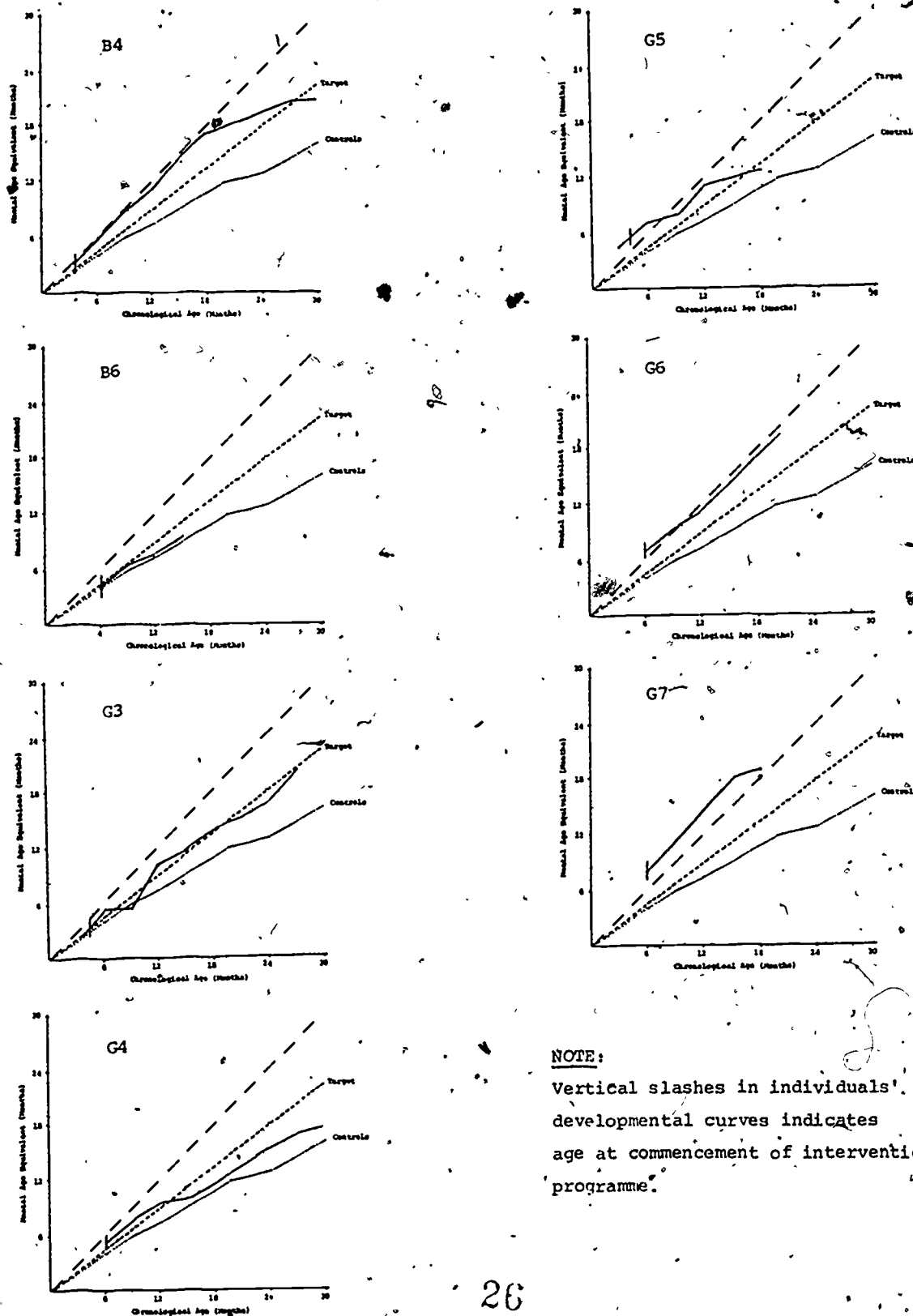
e Gain ratio = $\frac{\text{Mental Age on Exit} - \text{Mental Age on Entry}}{\text{C.A. on Exit} - \text{C.A. on Entry}}$

Mean of individual children's gain ratios, except for Cunningham and composite data

f Composite of several non-intervention studies

The series of graphs in Figures 3 and 4, too, clearly illustrate that individuals' performances are subject to fluctuation, with spurts and plateaus in development.

FIGURE 3
BAYLEY MENTAL DEVELOPMENT FOR DOWN'S SYNDROME CHILDREN
WHO COMMENCED PATH PROGRAMME < 8 MONTHS

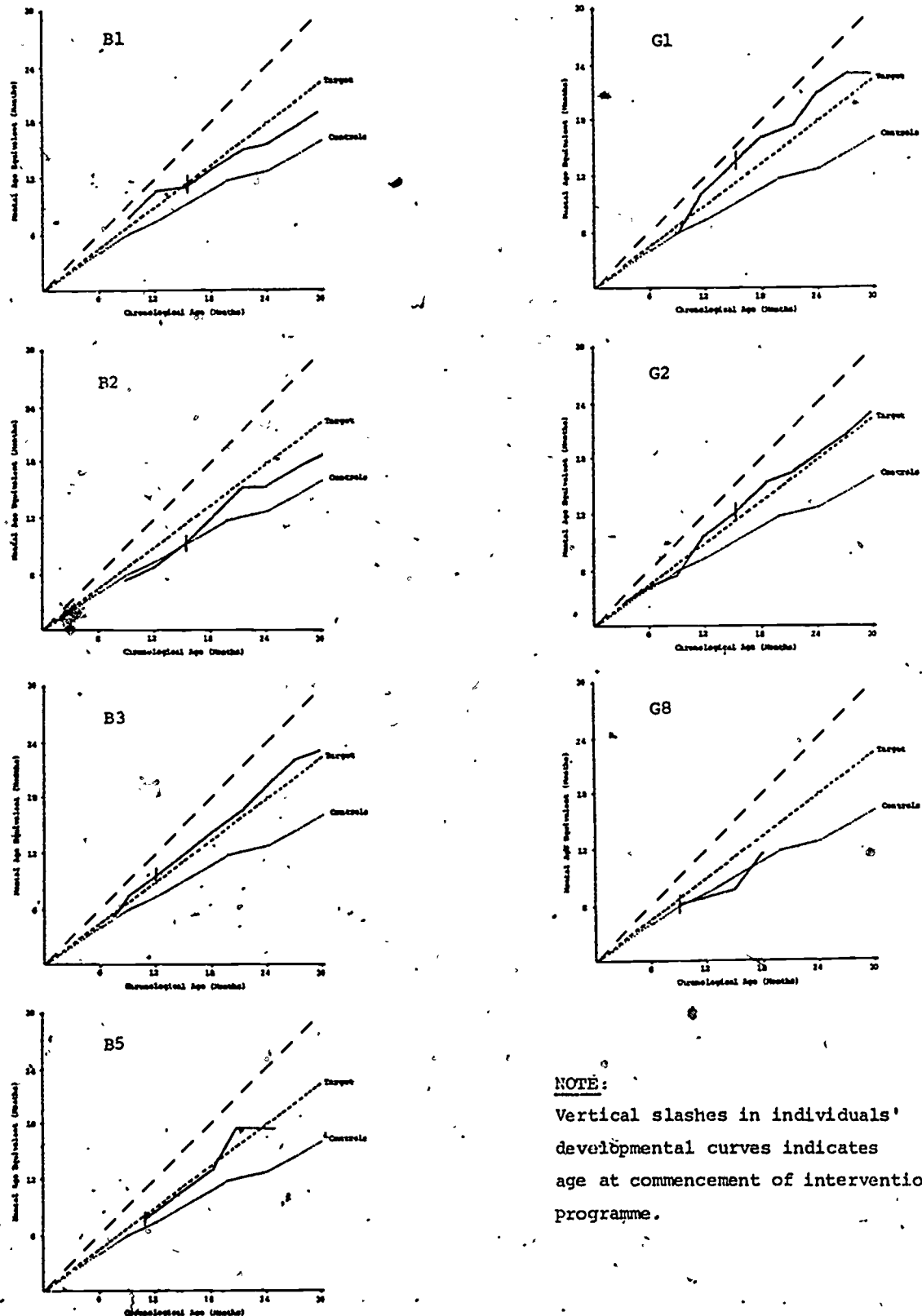


NOTE:

Vertical slashes in individuals' developmental curves indicates age at commencement of intervention programme.

FIGURE 4

BAYLEY MENTAL DEVELOPMENT FOR DOWN'S SYNDROME CHILDREN
WHO COMMENCED PATH PROGRAMME >8 MONTHS

NOTE:

Vertical slashes in individuals' developmental curves indicates age at commencement of intervention programme.

3.2 Motor Development

From Table 4 it can be seen that on the Motor Scale of the Bayley test, the PATH subjects achieved a mean gain ratio of .68, with a range from .38 (G3) to 1.06 (G2). These results are comparable to those obtained on the Mental Scale.

TABLE 4
INDIVIDUAL CHILDREN'S ENTRY AND EXIT SCORES
ON BAYLEY MOTOR SCALE : PATH DATA

Subject	Age on Entry	Motor Age Equiv. on Entry	PDI on Entry	Age on Exit	Motor Age Equiv. on Exit	PDI on Exit	Entry-Exit Motor Age Gains/C.A. Gains	Gain ratio
G1	15	12	77	36	22	70	10/21	.47
G2	15	10	73	31	27	88	17/16	1.06
G3	3	4	102	27	13	<50	9/24	.38
G4	6	5.5	86	30	18.5	50	13/24	.54
G5	4	4.5	111	18	13	56	8.5/14	.61
G6	6	6.5	110	20	19.5	97	13/14	.93
G7	7	7.5	115	18	19	107	11.5/11	1.05
G8	10	6	54	18	11.5	62	5.5/8	.69
B1	12	10	68	30	19	52	9/18	.50
B2	13	7.5	<50	30	19	52	11.5/17	.68
B3	12	9.5	70	30	23	73	13.5/18	.75
B4	3	3	98	30	20	60	17/27	.63
B5	11	8	62	24	17	62	9/13	.69
B6	5	4	80	15	9.5	<50	5.5/10	.55
\bar{x}	8.7	7.0		25.5	17.9			.68

The mean gain ratio of .68 for the PATH children held up for both the actual exit ages and for the adjusted exit age of 24 months. This ratio was considerably higher than that achieved by children receiving no or minimal intervention (.33) and, with the exception of the DMMSTART children (.62), of the ratios obtained in the comparison studies summarised in Table 5.

TABLE 5

COMPARISONS OF DOWN'S SYNDROME CHILDREN'S SCORES
ON BAYLEY MOTOR SCALE : ACROSS PROGRAMMES

Study	N	Entry			Exit			Gain ratio: ^e		
		\bar{X} C.A. (months)	\bar{X} Motor Age Equiv. (months)	Motor Age Equiv. C.A.	\bar{X} C.A. (months)	\bar{X} Motor Age Equiv. (months)	Motor Age Equiv. C.A.	M	F	T
PATH 1 ^a	14	8.7	7.0	80.5	25.5	17.9	70.2	.63	.72	.68
PATH 2 ^b	14	8.7	7.0	80.5	21.4	15.0	70.1	.64	.72	.68
DAWNSTART	6	5.0	2.8	56.0	21.5	12.8	59.5	-	-	.62
Foreman	13	3.1	3.1	100.0	21.5	11.1	51.6	.44	.51	.47
Berry 1 ^c	24	6.2	4.5	72.6	22.1	12.6	57.0	.52	.49	.51
Berry 2 ^d	24	6.2	4.5	72.6	20.0	11.5	56.2	.49	.48	.49
Cunningham	61	6.0	5.0	83.3	24.0	13.7	57.1	-	-	.48
Composite ^f	300+	9.0	6.0	66.7	24.0	11.0	45.8	-	-	.33

a Actual data at termination of project

b Data with maximum exit age taken at 24 months

c Actual data

d Data with maximum exit age taken at 24 months

e Gain ratio = $\frac{\text{Mental Age on Exit} - \text{Mental Age on Entry}}{\text{C.A. on Exit} - \text{C.A. on Entry}}$

Mean of individual children's ratios, except for Cunningham and Composite data

f Composite of several non-intervention studies

As with the Mental Scale, it is important to recognise that not only was there a large range in the distribution of the ratio scores among the children in the programme, but there was also considerable intra-individual variations in the children's motor performances over the duration of the project (see Figures 5 and 6). An interesting aspect of these graphs is the plateau in development which occurred for several of the children at around the age of 15 months (G3, B1, B2, G1, G2 and G8) - mainly because of slowness in the development of mobility skills.

3.3 Performances on Item Clusters on Bayley Scales

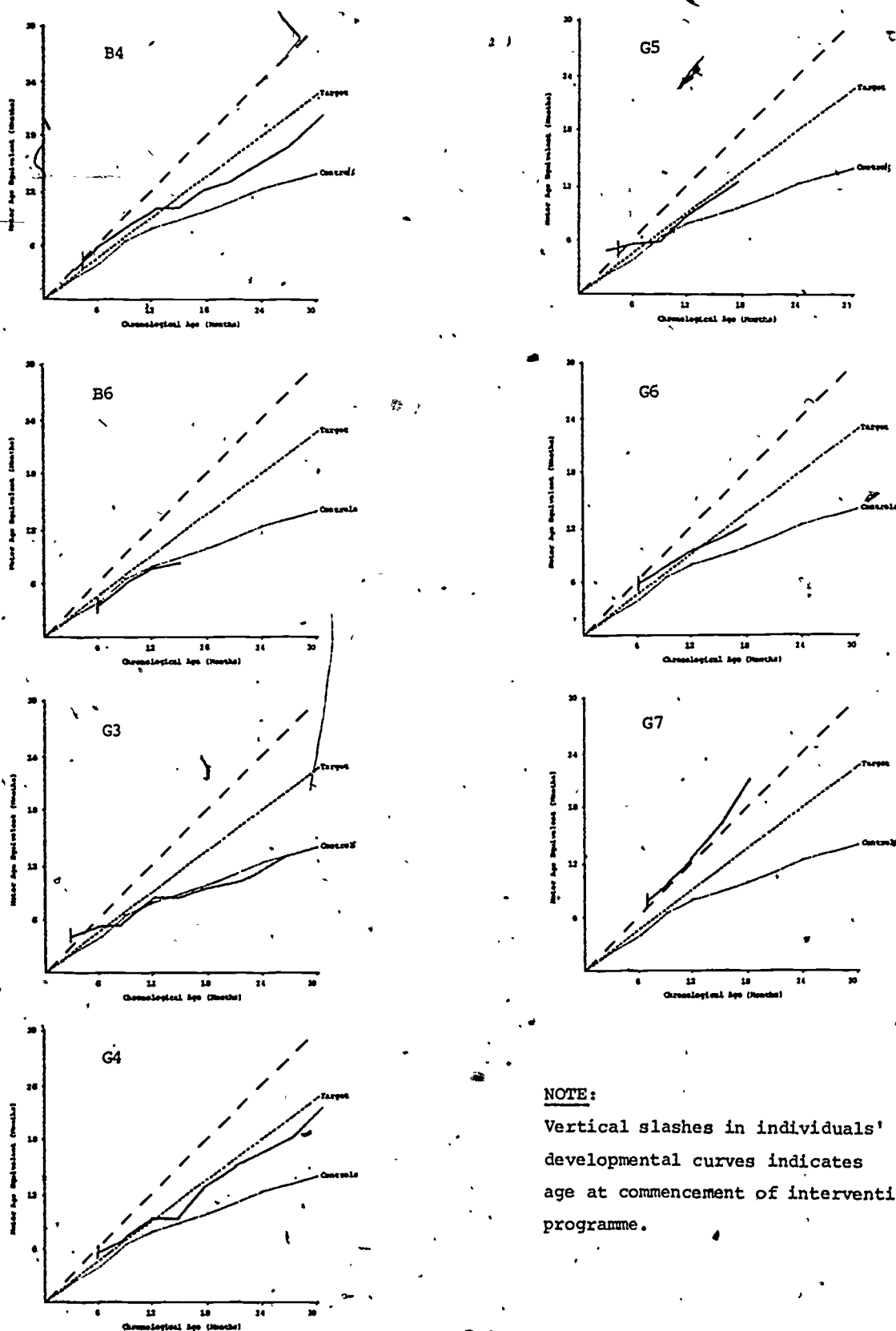
In order to ascertain the children's performance in developmental areas subsumed in the Bayley Scales, five skill clusters were identified in an *a priori* fashion. These were: (a) receptive language (e.g., responds to request, follows direction), (b) expressive language (e.g., vocalises attitudes, imitates words), (c) cognitive skills (e.g., unwraps cube, attains toy with a stick), (d) fine motor skills (e.g., picks up cube, puts beads in box), and (e) gross motor skills (e.g., sits alone, walks with help).¹

For each of these clusters the means and ranges of Bayley's normative sample and the means of the PATH subjects were plotted and are displayed in Figures 7-11. Two general points stand out from these graphs. Firstly, it can be seen that the Down's Syndrome children consistently scored towards the lower end of the range of the normative sample for most of the tests in receptive language (Figure 7), expressive language (Figure 8) and cognitive skills (Figure 9) until around 20-24 months, when wide gaps began to open up in the language clusters. In the case of the fine motor (Figure 10) and gross motor clusters (Figure 11), almost the reverse pattern applied, with quite large disparities between the lower end of the normative sample and the Down's Syndrome children's means until around 18-20 months when some evidence of convergence began to emerge. In interpreting these graphs, it should be noted that only incomplete data were available for children over the age of 18 months (see Table 2).

¹ Since this analysis was made, the writers became aware of Kohen-Raz's (1967) scalogram analysis of some developmental sequences in the Bayley Scales.

FIGURE 55

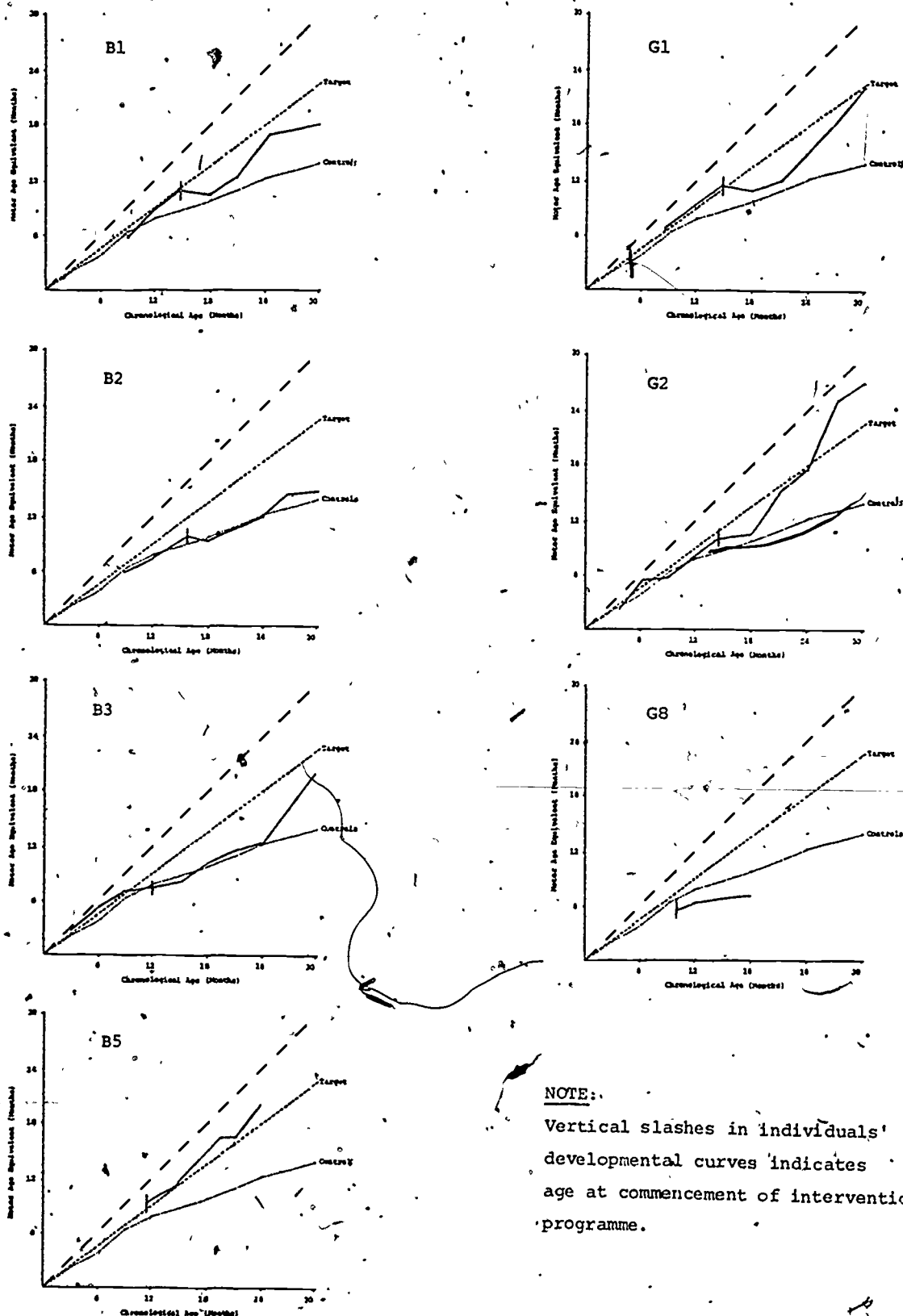
BAYLEY MOTOR DEVELOPMENT FOR DOWN'S SYNDROME CHILDREN
WHO COMMENCED PATH PROGRAMME <8 MONTHS

**NOTE:**

Vertical slashes in individuals' developmental curves indicates age at commencement of intervention programme.

FIGURE 6

BAYLEY MOTOR DEVELOPMENT FOR DOWN'S SYNDROME CHILDREN
WHO COMMENCED PATH PROGRAMME > 8 MONTHS



NOTE:

Vertical slashes in individuals' developmental curves indicates age at commencement of intervention programme.

The second point to be made about these graphs is that apart from a few minor deviations, the Down's Syndrome children followed the sequence of the Bayley items - and, hence, of normal development - a finding that provides some justification for using developmental norms as targets for intervention programmes.

3.3 Other Results

In addition to the above psychometric data, one of the therapists has written a personal account of her experiences in the project (see Appendix H). A follow-up of the children until they reach the age of five years has been planned. Although there has been some follow-up assessments since children were discharged from the programme, too few have been carried out to warrant presentation in this report. The senior author is also currently developing a scale for evaluating professionals' perceptions of parents, using Kelly's (1955) notions of personal constructs as elaborated in a recent publication edited by Slater (1976).

FIGURE 7

SCORES ON BAYLEY ITEMS RELATING TO RECEPTIVE LANGUAGE

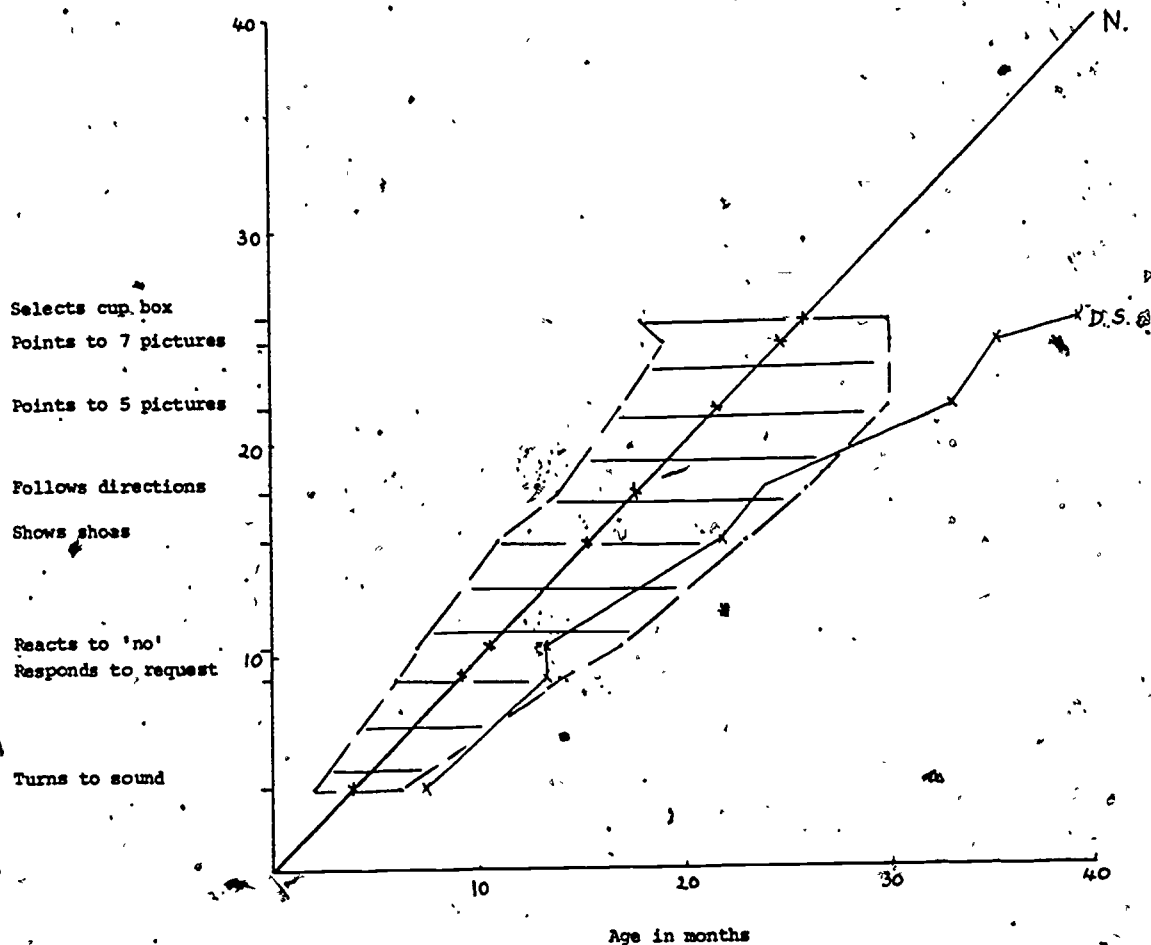


FIGURE 8

SCORES ON BAYLEY ITEMS RELATING TO EXPRESSIVE LANGUAGE

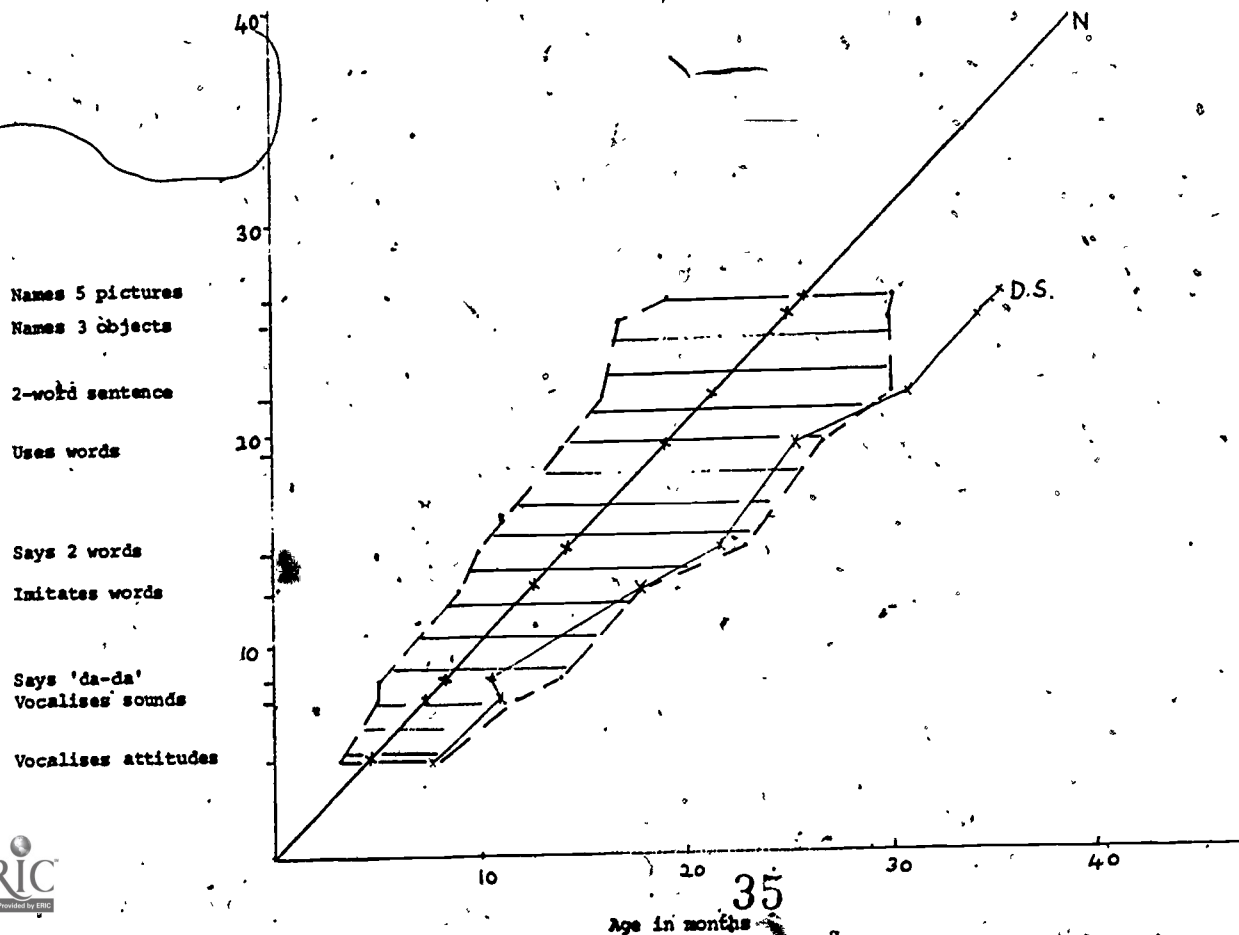


FIGURE 9

SCORES ON BAYLEY ITEMS RELATING TO COGNITIVE SKILLS

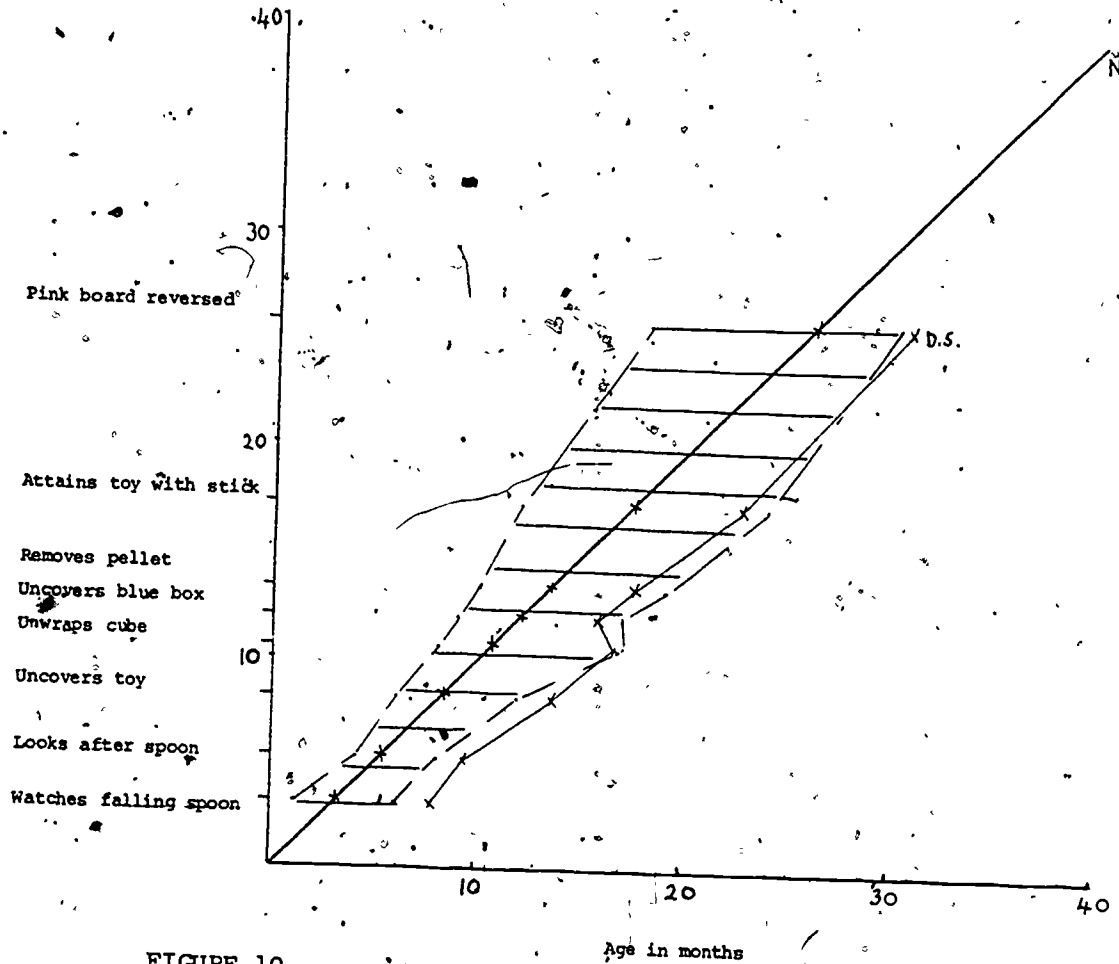


FIGURE 10
SCORES ON BAYLEY ITEMS RELATING TO FINE MOTOR SKILLS

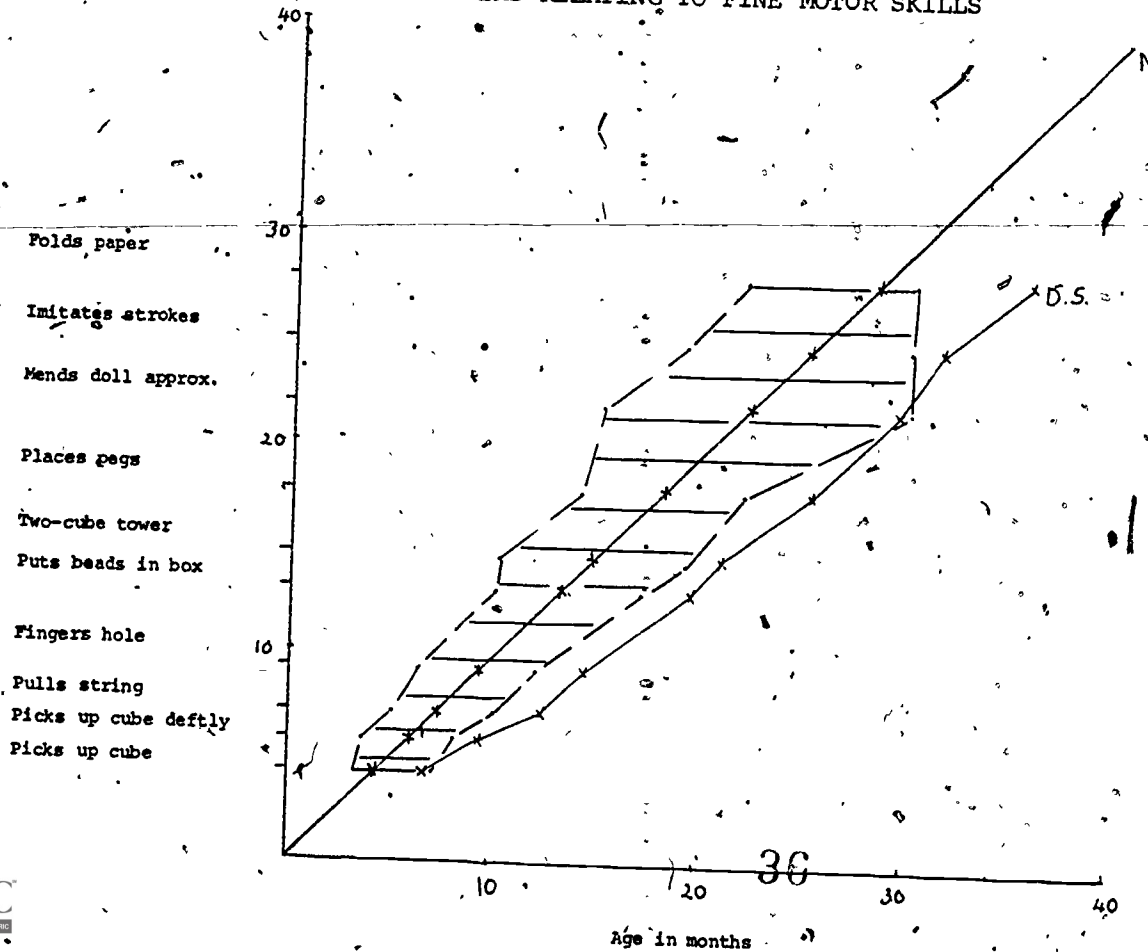
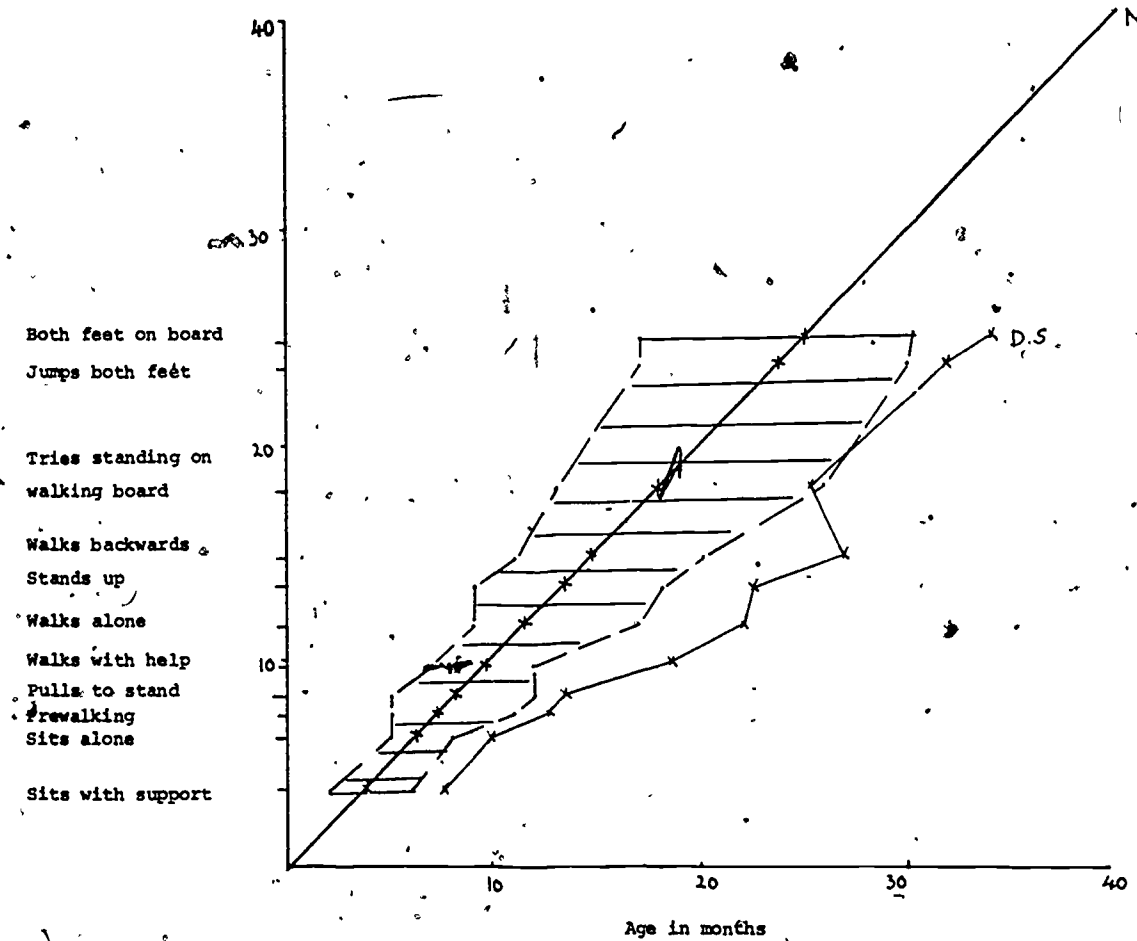


FIGURE 11

SCORES ON BAYLEY ITEMS RELATING TO GROSS MOTOR SKILLS



CHAPTER FOUR

SUMMARY AND CONCLUSIONS

4.1 Summary

The present study reports on the nature and results of an early intervention project involving 14 Down's Syndrome infants and their parents. The families were enrolled in the programme at a mean age of 8.7 months and were discharged at a mean age of 25.5 months. The families visited a university clinic once every two or three weeks, in the course of which the parents were given individualised guidance by a teacher and a physiotherapist. The children were assessed every three months on the Bayley Scales of Infant Development. On the Mental Scale, the children achieved a gain ratio of .70 - a result which is considerably higher than that achieved by children who have not received systematic intervention and towards the middle of the range of those who have. On the Motor Scale, a gain ratio of .68 was achieved, this ratio being higher than those reported in any of the studies with which comparisons can be made. These results suggest that in the first 24-30 months of life, a target of 70-75 per cent of average development is feasible for the majority of Down's Syndrome children.

4.2 Conclusions

Although this study provides some evidence in support of early intervention programmes, the following limitations must be taken into account when interpreting the results:

Firstly, it must be recognised that the study did not incorporate an untreated control group. While it is justified to compare the present results with other studies in which no intervention was given, such a procedure does not permit one to control for possible variations between communities or over time with respect to knowledge of and attitudes towards handicapping conditions.

Secondly, it is admitted that the intervention approach employed in the project was a "broad brush" one. Consequently, one cannot isolate with precision the particular variable or mix of variables that were present in the programme and which might have 'caused' the accelerated levels of development observed in the sample as a whole.

Thirdly, there is a possibility of a practice effect influencing the children's performance on the Bayley Scales. McCall (1977), however, has suggested that the effects of repeated testing in longitudinal research may not be very great and that the maximum effects, in any case, occur between the first two assessments.

Fourthly, there is the question of the relatively poor stability of the Bayley Scales in assessing infants. Horner (1980), for example, found that one-seventh of a sample of 9 and 15 month-old infants tested a week apart on the Mental Scale fluctuated as much as one standard deviation between testings. Provided one does not make too much of variations in the performances on the tests between occasions for particular individuals (a point we had to emphasise to the parents), this should not have too serious an effect on the overall pattern of results reported in this study.

And, finally, there is the issue of the predictive validity of the performances on the Bayley Scales. In other words, what is the likelihood of the scores achieved at the end of the programme being sustained in the future? Lewis and McGurk (1974) and Elkind (1974), for example, have criticised the use of infant intelligence tests in infant stimulation programmes on the grounds that what is being stimulated in these programmes are the very same sensori-motor skills which appear in infant intelligence scales and which have little relation to intelligence as it appears later in life. On the other hand, Dubose (1976), Hunt (1976) and Ramey, Campbell and Nicholson (1973) have presented evidence suggesting that two-year olds' Bayley scores are highly correlated with I.Q. test scores at later ages. Perhaps the appropriate "middle view" to adopt is that of Siegel (1981) who has pointed out that infant tests account for, at best, only 50 per cent of the variance for later development, with factors such as stimulating environments playing a critical role in mediating developmental outcomes.

To conclude, even when account is taken of the above limitations, the data obtained in this study suggest that appropriate intervention through training parents in the principles and practices of structured teaching can enhance the development of Down's Syndrome infants. If the results achieved in this and comparable studies are extrapolated into future development, Down's Syndrome children should be perceived as having the potential to function in the mildly retarded range, with some having the capacity to function in the lower end of the average range - a far cry from their classification not so many years ago as "imbeciles". The results, then, lend further weight to the increasing body

of evidence from other programmes, both in New Zealand and overseas, pointing to the necessity for making early intervention an integral part of our education system.

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APPENDIX A
CHARACTERISTICS OF SUBJECTS IN DAWNSTART

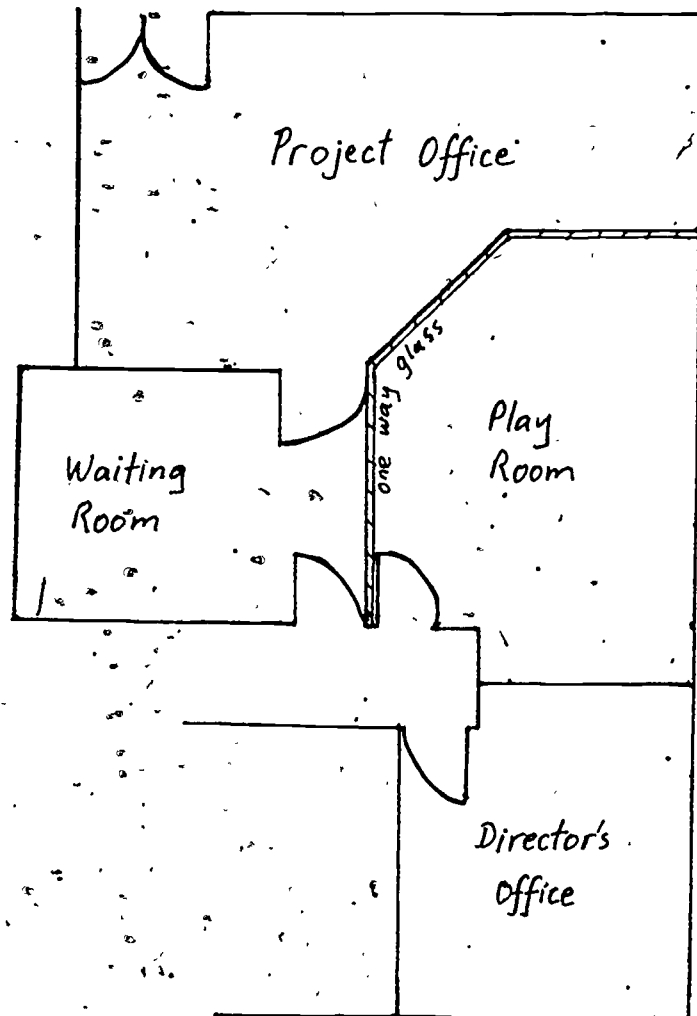
Variable	F1	F2	M1	M2	M3	M4
Mother's age at birth	41	33	39	32	33	38
Father's age at birth	42	35	36	33	24	32
Family's SES ¹	2	1	3	3	5	5
Ordinal position of child at birth ¹	$\frac{4}{4}$	$\frac{3}{3}$	$\frac{6}{6}$	$\frac{1}{2}$	$\frac{3}{3}$	$\frac{2}{2}$
Birthweight (in grams)	3288		1474			
When parents informed ²	Birth	12m	Birth	Birth	Birth	Birth
Which parents informed ³	B	B	B	B	M	M
Physical abnormalities	Vision	Deform. Ankles	Heart murmur	Squint	Heart murmur	Vision
Distance from clinic (in kilometres)	5	23	15	16	3	2
Age at entry to intervention	4m	14m	3m	3m	3m	6m
Age at exit from intervention	24m	24m	20m	22m	24m	18m

¹ Elley and Irving (1976) Index

² Numerator = place in family; denominator = number in family

³ M = Mother first; B = both together

APPENDIX B
PLAN OF CLINIC



Scale: 1cm = 1m

APPENDIX C

Examples of PATHWAYS Programme used with Families

ANGELA 10.3.80

Please continue with(1) "Building up strength" in hands using
bean bags; heavier objects

(2) Action imitations - any time during the day

1. Using thumb and fingers to pick up small objects

- (1) small doll's cup (2) small plastic cup
- (3) piece of string (4) crumb/raisin
- (5) anything you can think of that Angela might enjoy picking up.
- (A) Watch and see if Angela uses 2 or more fingers to pick up objects.
- (B) Sit slightly behind her. Put your hand over hers using your forefinger and thumb, press her forefinger and thumb together to pick up an object.
- (C) Tell her what you are both doing.
- (D) Praise her for any suitable attempts.
- (E) Lighten your touch next time.
- (F) Try 2 or 3 more times; keep reducing help as Angela becomes more used to the game..

2. Putting objects in containers

- (1) Choose some familiar, not too interesting objects (otherwise she won't release them) :
e.g. Margarine container
- (A) When Angela is playing, clear away the distracting toys.
- (B) Sit in front of her.
- (C) Put the container right in front of Angela. (Hold it so she can't take it).
- (D) Make sure you have Angela's attention.
- (E) Say "Put the block in the box" as you do this.
- (F) Do the action again.
- (G) Give 'Angela' the block and say "You put the block in the bowl".
- (H) Use hand over hand : Lots of praise : Let Angela play with the bowl/block when you've finished.
- (I) Use different containers: large/small ones : different objects

TIMOTHY P. 18.8.81

Continue with wide range of activities as suggested in F.M.6. Remember these are suggestions for activities and it is not intended that each and every activity is to be worked at within a short space of time.

- Select those that
- have particular interest for Tim
 - have not been used for some time
 - add a touch of difference.

Timothy is now at a stage where he has a wide understanding of language although he is not yet using it himself. Over the next period of time the focus of attention needs to be on expressive language

- be alert for his attempts: - these need to be reinforced just as much (perhaps even more) as clearly spoken words
- listen during his free play time
- listen particularly when he particularly wants an object/food/drink (perhaps of a particular kind)
- listen when you present him from time to time with a "forced choice" e.g. "Would you like some toast or some apple?" with both being out of his vision so he has to attempt - note that both foods have different initial consonants, are relatively short, with hopefully little confusion between the two being an outcome.
- try making a cut out picture book with Tim, the pictures to be of objects that hold particular interest for him. Encourage him to attempt to say. **NECESSARY FOR SUCCESS THAT EACH AND EVERY ATTEMPT IN INITIAL STAGES BE CLEARLY AND HEAVILY REINFORCED.**
- try including pictures of action - (verbs).
Pictures of actions which may have high appeal are those showing people (boys girls babies etc.) or animals

smiling	drinking
crying	running
eating	climbing
riding	brushing (hair/teeth)
- try asking a question or two during story book time - praise his attempt. (Beware of using this too much at any one time!).

APPENDIX D

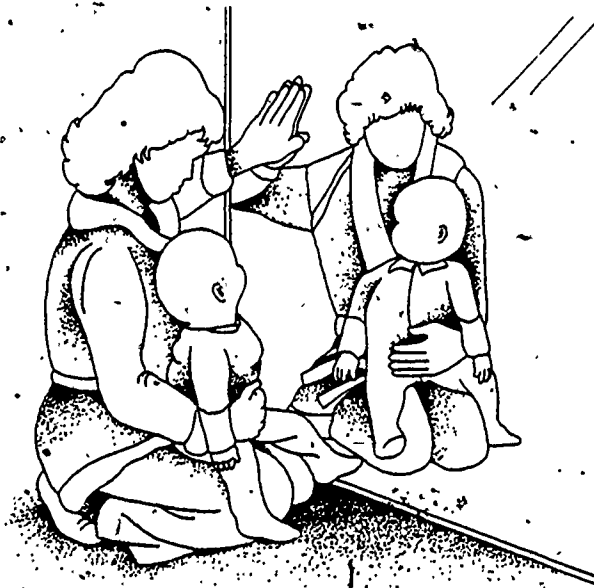
Sample of PATHWAYS Manual

LOOKING AND THINKING

TS 1.2

Looking around to find outHOW do we help?

1. A bassinette with see-through sides or a see-through panel is excellent for encouraging your baby to look around.
2. Babies don't always have to sleep in their own room. Try having him out with you in the living room during the day. He'll thoroughly enjoy listening to the sounds around him before he falls off to sleep.
3. Try his bassinette in different positions in his room so that he isn't always getting the same view of the room from the same angle. Every now and then move his bassinette into a different room so that he has new patterns of light and shade to watch and different activities going on around him. Make these changes when you think your baby has become used to a particular position.
4. Does your baby lie a lot with his head turned to one particular side? To encourage him to turn his head and look to the other side, you could:
 - * Place an open hard cardboard type book in the side of his bassinette where he doesn't usually look. Change the page each day. You could also try a small, soft toy.
 - * Change the position of his bassinette within the room.
 - * Hold him up to a mirror, fully supported against your body:



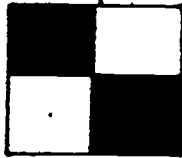
Mirrors will fascinate babies

LOOKING AND THINKING

TS 1.3

Looking at a mobile*Before you start*

1. Make a mobile of 3 cards, each with a two by two black and white check on both sides, or with a face:



2. In activities like this, you'll want to be able to watch your baby's eyes to find out what he's looking at. Find a way to do this that doesn't make him notice you - or he'll look at your face instead of the mobile.
3. Make sure your baby is feeling contented and ready to play, and that the mobile is hung in a place where it is easy for him to see it.

HOW do we help?

1. Hang the mobile about 12-25 cm (5-10 inches) above your baby's face, slightly to one side of his head. Watch him carefully and see how often he looks at the mobile. When he starts deliberately seeking it with his eyes, you'll know that looking at the mobile has become satisfying to him.



Babies like face mobiles

LOOKING AND THINKING

2. If he doesn't look at the mobile:

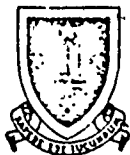
- (a) Try gently guiding his head (your hands on either side of his face) until he's looking straight at the mobile.
- (b) Let him look at it, then take your hands away. He'll probably lose the mobile, but give him a chance to find it again before you help him any more.
- (c) As he gets better at finding the mobile by himself, gradually reduce the help you give him.



Mobiles are fun

APPENDIX E

LETTER TO REFERRAL AGENTS



University of Waikato

PRIVATE BAG, HAMILTON, NEW ZEALAND: TELEPHONE 62 889

PROJECT PATH

Dear Dr

Re:

of:

This child was originally referred to us by _____

_____ has been attending our clinic with _____ since _____ and is currently enrolled in the intervention phase of the project. Accordingly is attending every fortnight.

In _____ most recent assessment on the Bayley Test of Infant Development on _____ aged _____ months showed a developmental level of around _____ months on the Mental Scale and of around _____ months on the Motor Scale of the test.

Our programme over the next three months will be concentrating on the following areas:

Fine motor :
Receptive Language :
Gross motor :

We shall send you these brief progress reports after each three-monthly assessment. In order to keep us fully informed about other factors which might be influencing _____ development, we would be most grateful if you could let us know of anything of importance which comes to your notice regarding _____ We would be particularly interested in any medication or change in medication for this child.

If there are any further details you would like from us, please do not hesitate to contact me.

Yours sincerely,

D. R. MITCHELL
Senior Lecturer in Education
Director, Project PATH

APPENDIX F

INDIVIDUAL CHILDREN'S ENTRY AND EXIT SCORES
ON BAYLEY MENTAL SCALE : DAWNSTART DATA

Subject	Age on Entry	Mental Age Equiv. on Entry	MDI on Entry	Age on Exit	Mental Age Equiv. on Exit	MDI on Exit	Entry-Exit M.A. Gains/C.A. Gains	Gain ratio
F1	6	3	50	24	17	61	14/18	.78
F2	15	11	60	24	22	89	11/9	1.22
M1	3	2	79	18	14	62	12/15	.80
M2	3	1	<50	21	16	60	15/18	.83
M3	3	1	<50	24	19	72	18/21	.85
M4	6	1	<50	18	9	<50	8/12	.66
\bar{X}	5.0	3.2		21.5	16.2			.86

APPENDIX G

INDIVIDUAL CHILDREN'S ENTRY AND EXIT SCORES
ON BAYLEY MOTOR SCALE : DAWNSTART DATA

Subject	Age on Entry	Motor Age Equiv. on Entry	PDI on Entry	Age on Exit	Motor Age Equiv. on Exit	PDI on Exit	Entry - Exit Motor Age Gains/C.A. Gains	Gain ratio
F1	6	2	<50	24	14	<50	12/18	.67
F2	15	9	<50	24	12	<50	3/9	.33
M1	3	1	<50	18	10	<50	9/15	.60
M2	3	2	79	21	14	<50	12/18	.67
M3	3	1	<50	24	16	53	15/21	.71
M4	6	2	<50	18	11	<50	9/12	.75
\bar{X}	5.0	2.8		21.5	12.8			.62

APPENDIX H

COMMENTS BY ONE OF THE THERAPISTS

Eighteen months with the Project's parents and their young children has given me a greater understanding of the nature of Down's Syndrome and an appreciation of parents' courage and adaptability in taking on a specialized teaching role.

My comments will focus mainly on the parents' teaching abilities and on possible directions for future research.

Firstly, parents acquired the teaching skills of modelling, physical prompting and avoidance of inappropriate child behaviours very quickly but tended to rely on non-specific positive reinforcement "Good girl!". Helping parents to select positive reinforcers, a favourite toy, physical contact or a piece of toast, that were singularly meaningful for their child became an important part of the teaching programme.

Fine motor, gross motor, cognitive and receptive language activities were easily taught and were enjoyed by the parents and their children; stimulating and shaping the expressive language of Down's infant took time and much perseverance.

Since the consistent use of a rigorous behavioural approach led, in some cases, to resistance on the part of the child and disappointment on the part of the parent, parents adopted alternative teaching strategies, parallel-play methods or a child-centred approach where the child initiates the activity and teaching is based on the child's current interest.

Secondly, the process of teaching parents how to teach their children was different for each parent-child dyad. Some parents found task analysis easy, some didn't; some parents were very creative in designing materials and activities while others required step-by-step instruction until they gained more confidence as teachers. Possibly the ability to teach a parent is dependent upon two factors: the honest, though empathic, two-way communication between parent and therapist and the parent's confidence in the therapist's expertise.

Thirdly, it is during the Down's child's second year, when developmental milestones of walking and talking are not met that parents need more emotional support, support that is optimistic but realistic.

Fourthly, a few thoughts on the possible directions of future research. From my experience of the benefits of "home-visits", I would suggest that future intervention projects combine clinic-centred with home-based programmes and employ a range of teaching methods.

From my awareness of the developmental lag in Down's infants' expressive language I would urge further research into the acquisition of non-verbal and verbal communication.

Finally, I would suggest that prior to commencement in an early intervention programme, therapists should commit themselves to a fairly rigorous training in communication and counselling skills and to learning a variety of teaching strategies, including behavioural approaches.

In conclusion a note of appreciation to the parents and their young children from whom I learned more than I ever taught.

Martha Parker